



PARTICIPANT EXPERIENCE SURVEY



MR/DD VERSION

Version 1.0
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A Technical Assistance Tool for States

DEVELOPED BY
The MEDSTAT Group, Inc.
FOR THE
Centers for Medicare & Medicaid Services
AN AGENCY OF
The Department of Health & Human Services
CONTRACT #500-96-0006 T.O. #2

THOMSON

MEDSTAT

CMS

CENTERS for MEDICARE & MEDICAID SERVICES

Survey Instructions

- * Make sure you have the respondent's face sheet available when conducting the interview, since you are directed to refer to it at various points during the interview.
- * Text read to the respondent is in mixed case. Text just for you is in all CAPS (with the exception of the Interviewer Comments Section).
- * Please answer every question by checking **one** box, ☒ unless instructed to "Check all that apply," in which case multiple boxes may be checked.
- * Do not leave any questions blank. If the respondent does not answer an item, check the box for "No Response."
- * Record **only** responses provided by the respondent.
- * Some questions require you to write in the respondent's answer, like the example below. Please record the respondent's verbatim response as best you can.

66. What kind of work do you do? (SPECIFY)

- * Some questions are skipped over in this survey. When this is necessary, an arrow directs you to the next question to be asked, like the example below.

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.15
- 7 ☐ UNSURE →Skip to Q.17
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.17
- 9 ☐ NO RESPONSE →Skip to Q.17

- * If there is no arrow next to a response category, like the "YES" response above, please continue with the very next item in the sequence.
- * Some items have instruction boxes, like the example below. These boxes are intended to provide you with additional information or instructions. Do not read these to the respondent.

- | | | | |
|---|---|-------------------------------------|--|
| Refer to the face sheet for the case manager's or support coordinator's name. | 1 | <input type="checkbox"/> | NAMES CASE MANAGER/SUPPORT COORDINATOR |
| | 2 | <input checked="" type="checkbox"/> | DOES NOT NAME CASE MANAGER/SUPPORT COORDINATOR |
| | 8 | <input type="checkbox"/> | UNCLEAR RESPONSE |
| | 9 | <input type="checkbox"/> | NO RESPONSE |

- * Some questions are in bold, these are the core questions for program participants with severe cognitive impairments. For more detail about using the core questions, see p. 16 in the Users' Guide.

PARTICIPANT EXPERIENCE SURVEY MR/DD

Hello, my name is _____ and I am from _____. How are you today? Thank you again for letting me come talk with you. I am very interested in hearing about your life and how happy you are with the help you get from your support staff. If you have any questions, please stop me and ask me. Also, please let me know if you do not understand a question or if you would like me to repeat it. Are you ready to begin?



Case ID#: _____ Interviewer Name: _____ Date: _____

A. Choice and Control

The first questions I'd like to ask you have to do with where you live.

1. How long have you lived (in your home/here)?

_____ YEARS _____ MONTHS

*If appropriate,
round to the
nearest number of
years. Estimates
are fine.*

- 7 ☐ UNSURE
8 ☐ UNCLEAR RESPONSE
9 ☐ NO RESPONSE

2. Do you like where you live?

- 1 ☐ YES
2 ☐ NO
3 ☐ SOMETIMES
7 ☐ UNSURE
8 ☐ UNCLEAR RESPONSE
9 ☐ NO RESPONSE

3. Did you help pick (this/that) place to live?

- 1 ☐ YES
2 ☐ NO
7 ☐ UNSURE
8 ☐ UNCLEAR RESPONSE
9 ☐ NO RESPONSE

4. CODE LIVING SITUATION AS INDICATED ON FACE SHEET.

- 1 ☐ HOUSEMATES
- 2 ☐ FAMILY
- 3 ☐ ALONE

5. According to _____, you live with (housemates/your family/by yourself). Is that right?
(CHECK CORRECT CATEGORY)

*Refer to face
sheet for
respondent's living
situation and the
name of the
person providing
background
information.*

- 1 ☐ HOUSEMATES → Skip to Q.8
- 2 ☐ FAMILY → Skip to Q.7
- 3 ☐ ALONE
- 7 ☐ UNSURE → Skip to Q.11
- 8 ☐ UNCLEAR RESPONSE → Skip to Q.11
- 9 ☐ NO RESPONSE → Skip to Q.11

6. Did you choose to live alone?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE



7. Would you rather live with other people?

- 1 ☐ YES →Skip to Q.11
- 2 ☐ NO →Skip to Q.11
- 7 ☐ UNSURE →Skip to Q.11
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.11
- 9 ☐ NO RESPONSE →Skip to Q.11

8. **Do you like the people you live with?**

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

9. Do you share a bedroom in your home?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.11
- 7 ☐ UNSURE →Skip to Q.11
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.11
- 9 ☐ NO RESPONSE →Skip to Q.11

10. Did you help pick the person who shares your bedroom?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

11. Now let's talk about the people who help you. Do you help pick your support staff?

- 1 ☐ YES →Skip to Q.13
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.13
- 9 ☐ NO RESPONSE →Skip to Q.13
- 95 ☐ NO SUPPORT STAFF →Skip to Q.16

12. Would you like to help pick your support staff?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

13. Did you know you can change your support staff if you want?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

14. Do you tell your support staff what to help you with?

- 1 ☐ YES →Skip to Q.16
- 2 ☐ NO
- 3 ☐ SOMETIMES →Skip to Q.16
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.16
- 9 ☐ NO RESPONSE →Skip to Q.16



15. Would you like to tell them the things you want help with?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

16. When you are at home, can you eat when you want to?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

17. Can you watch TV when you want to?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

18. Can you go to bed when you want to?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

19. Can you be by yourself when you want to?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

20. If there is something wrong with the help you are getting, who do you talk with to get the problem fixed? (CHECK ALL THAT APPLY)

*Probe,
if necessary,
to place the
response in the
appropriate
category.*

- 1 ☐ NO ONE
- 2 ☐ FAMILY/FRIEND
- 3 ☐ CASE MANAGER/SUPPORT COORDINATOR/OTHER STAFF
- 4 ☐ OTHER (SPECIFY) _____
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

21. Who is your case manager or support coordinator?

*Refer to the face
sheet for the case
manager's or
support
coordinator's
name.*

- 1 ☐ NAMES CASE MANAGER/SUPPORT COORDINATOR
- 2 ☐ DOES NOT NAME CASE MANAGER/SUPPORT COORDINATOR
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE



22. Can you talk to your case manager or support coordinator when you need to?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE
- 95 ☐ NOT APPLICABLE – HAS NOT TRIED

23. Does your case manager or support coordinator help you when you ask for something?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE
- 95 ☐ NOT APPLICABLE – HAS NOT ASKED

24. What do you do during the day? (SPECIFY)

BOX 1

REVIEW RESPONSE AT Q.24.

IF RESPONDENT HAS A FORMAL DAILY ACTIVITY, ASK Q.25.
OTHERWISE, SKIP TO Q.27.

25. Do you like your (job/day program/volunteer work)?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

26. Did you help pick the (job/day program/volunteer work) you go to now?

- 1 ☐ YES →Skip to Q.30
- 2 ☐ NO →Skip to Q.30
- 7 ☐ UNSURE →Skip to Q.30
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.30
- 9 ☐ NO RESPONSE →Skip to Q.30

27. Do you want to work?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

28. Would you like to go to a day program?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE



29. Would you like to do volunteer work?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

B. Respect/Dignity

Next I would like to ask some questions about how your support staff treat you.

30. Do the support staff who come to your home respect you?

Refer to the face
sheet for names of
home support
staff.

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE
- 95 ☐ NO STAFF IN HOME → Skip to Q.33

31. Do the support staff who come to your home say "please" and "thank you" when they ask you for something?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

32. Do the support staff who come to your home listen carefully to what you ask them to do?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

33. Do the support staff in other places, such as at work, or at a day program, respect you?

*Use specifics from
face sheet about
services provided
outside the home
and staff names.*

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE
- 95 ☐ NO SERVICES OUTSIDE THE HOME → Skip to Q.36

34. Do the support staff in other places, such as at work, or at a day program, say "please" and "thank you" when they ask for something?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

35. Do the support staff in other places, such as at work, or at a day program, listen carefully to what you ask them to do?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

36. Do you use a van to get to the places you need to go, such as work or the doctor's office?

- 1 ☐ YES
- 2 ☐ NO → Skip to Q.40
- 7 ☐ UNSURE → Skip to Q.40
- 8 ☐ UNCLEAR RESPONSE → Skip to Q.40
- 9 ☐ NO RESPONSE → Skip to Q.40

37. Do the support staff on the van respect you?

*Use specifics from
face sheet about
services provided
outside the home
and staff names.*

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

38. Do the support staff on the van say "please" and "thank you" when they ask for something?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

39. Do the support staff on the van listen carefully to what you ask them to do?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE



40. Do people ever come into your room when you don't want them to?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

41. Does anyone take your things without asking first?

Reminder:

Refer to your state's policy on reporting for any suspected incidents of abuse and neglect. Record only reports of current abuse.

- 1 ☐ YES
- 2 ☐ NO → Skip to Q.45
- 3 ☐ SOMETIMES
- 7 ☐ UNSURE → Skip to Q.45
- 8 ☐ UNCLEAR RESPONSE → Skip to Q.45
- 9 ☐ NO RESPONSE → Skip to Q.45

42. What happens? Would you like to tell someone about this? (SPECIFY)

43. Who takes your things without asking first? (SPECIFY)

44. How do you know (this person/these people)? (CHECK ALL THAT APPLY)

Probe, if necessary, to place the response in the appropriate category.

- 1 ☐ SUPPORT STAFF AT HOME
- 2 ☐ SUPPORT STAFF SOMEWHERE ELSE
- 3 ☐ HOUSEMATE
- 4 ☐ FAMILY/FRIEND
- 5 ☐ OTHER (SPECIFY) _____
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

45. Does anyone ever do mean things to you, such as yell at you?

Reminder:
Refer to your state's policy on reporting for any suspected incidents of abuse and neglect. Record only reports of current abuse.

- 1 ☐ YES
- 2 ☐ NO → Skip to Q.49
- 3 ☐ SOMETIMES
- 7 ☐ UNSURE → Skip to Q.49
- 8 ☐ UNCLEAR RESPONSE → Skip to Q.49
- 9 ☐ NO RESPONSE → Skip to Q.49

46. What happens? Would you like to tell someone about this? (SPECIFY)

47. Who is mean to you or yells at you? (SPECIFY)

48. How do you know (this person/these people)? (CHECK ALL THAT APPLY)

Probe, if necessary, to place the response in the appropriate category.

- 1 ☐ SUPPORT STAFF AT HOME
- 2 ☐ SUPPORT STAFF SOMEWHERE ELSE
- 3 ☐ HOUSEMATE
- 4 ☐ FAMILY/FRIEND
- 5 ☐ OTHER (SPECIFY) _____
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

49. Does anyone ever hit you or hurt your body?

Reminder:
Refer to your state's policy on reporting for any suspected incidents of abuse and neglect. Record only reports of current abuse.

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.53
- 3 ☐ SOMETIMES
- 7 ☐ UNSURE →Skip to Q.53
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.53
- 9 ☐ NO RESPONSE →Skip to Q.53

50. What happens? Would you like to tell someone about this? (SPECIFY)

51. Who hits you or hurts your body? (SPECIFY)

52. How do you know (this person/these people)? (CHECK ALL THAT APPLY)

*Probe, if
necessary, to
place the
response in the
appropriate
category.*

- 1 ☐ SUPPORT STAFF AT HOME
- 2 ☐ SUPPORT STAFF SOMEWHERE ELSE
- 3 ☐ HOUSEMATE
- 4 ☐ FAMILY/FRIEND
- 5 ☐ OTHER (SPECIFY) _____
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE



C. Access to Care

This next set of questions I am going to ask you have to do with some everyday activities, such as getting dressed and taking a bath.

53. Is there any special help that you need to take a bath or shower? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ NEEDS HELP FROM ANOTHER PERSON
- 2 ☐ DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.56
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.56
- 9 ☐ NO RESPONSE →Skip to Q.56

54. Do you ever go without a bath or shower when you need one?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.56
- 7 ☐ UNSURE →Skip to Q.56
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.56
- 9 ☐ NO RESPONSE →Skip to Q.56

55. Is this because there is no one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSEEnter text hereE

56. Is there any special help that you need to get dressed? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ NEEDS HELP FROM ANOTHER PERSON
- 2 ☐ DOES NOT NEED HELP FROM ANOTHER PERSON → Skip to Q.59
- 8 ☐ UNCLEAR RESPONSE → Skip to Q.59
- 9 ☐ NO RESPONSE → Skip to Q.59

57. Do you ever go without getting dressed when you need to?

- 1 ☐ YES
- 2 ☐ NO → Skip to Q.59
- 7 ☐ UNSURE → Skip to Q.59
- 8 ☐ UNCLEAR RESPONSE → Skip to Q.59
- 9 ☐ NO RESPONSE → Skip to Q.59

58. Is this because there is no one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE



59. Is there any special help that you need to get out of bed? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ NEEDS HELP FROM ANOTHER PERSON
- 2 ☐ DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.62
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.62
- 9 ☐ NO RESPONSE →Skip to Q.62

60. Do you ever go without getting out of bed when you need to?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.62
- 7 ☐ UNSURE →Skip to Q.62
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.62
- 9 ☐ NO RESPONSE →Skip to Q.62

61. Is this because there is no one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

62. Is there any special help that you need to eat? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ NEEDS HELP FROM ANOTHER PERSON
- 2 ☐ DOES NOT NEED HELP FROM ANOTHER PERSON → Skip to Q.65
- 8 ☐ UNCLEAR RESPONSE → Skip to Q.65
- 9 ☐ NO RESPONSE → Skip to Q.65

63. Do you ever go without eating when you need to?

- 1 ☐ YES
- 2 ☐ NO → Skip to Q.65
- 7 ☐ UNSURE → Skip to Q.65
- 8 ☐ UNCLEAR RESPONSE → Skip to Q.65
- 9 ☐ NO RESPONSE → Skip to Q.65

64. Is this because there is no one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

65. Is there any special help that you need to make your meals? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ NEEDS HELP FROM ANOTHER PERSON
- 2 ☐ DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.68
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.68
- 9 ☐ NO RESPONSE →Skip to Q.68
- 95 ☐ NOT APPLICABLE, TUBE FED →Skip to Q.71

66. Do you ever go without a meal when you need one?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.68
- 7 ☐ UNSURE →Skip to Q.68
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.68
- 9 ☐ NO RESPONSE →Skip to Q.68

67. Is this because there is no one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

68. Is there any special help that you need to get groceries? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ NEEDS HELP FROM ANOTHER PERSON
- 2 ☐ DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.71
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.71
- 9 ☐ NO RESPONSE →Skip to Q.71

69. Are you sometimes unable to get groceries when you need them?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.71
- 7 ☐ UNSURE →Skip to Q.71
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.71
- 9 ☐ NO RESPONSE →Skip to Q.71

70. Is this because there is no one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE



71. Is there any special help that you need to do housework? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ NEEDS HELP FROM ANOTHER PERSON
- 2 ☐ DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.74
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.74
- 9 ☐ NO RESPONSE →Skip to Q.74

72. Does the housework not get done sometimes?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.74
- 7 ☐ UNSURE →Skip to Q.74
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.74
- 9 ☐ NO RESPONSE →Skip to Q.74

73. Is this because there is no one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

74. Is there any special help that you need to do laundry? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ NEEDS HELP FROM ANOTHER PERSON
- 2 ☐ DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.77
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.77
- 9 ☐ NO RESPONSE →Skip to Q.77

75. Does the laundry not get done sometimes?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.77
- 7 ☐ UNSURE →Skip to Q.77
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.77
- 9 ☐ NO RESPONSE →Skip to Q.77

76. Is this because there is no one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

77. Can you always get to the places you need to go, like work, shopping, the doctor's office, or a friend's house?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

78. Is there any special help that you need to take medicine, such as someone to pour it or set up your pills? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ NEEDS HELP FROM ANOTHER PERSON
- 2 ☐ DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.81
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.81
- 9 ☐ NO RESPONSE →Skip to Q.81

79. Do you ever go without taking your medicine when you need it?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.81
- 7 ☐ UNSURE →Skip to Q.81
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.81
- 9 ☐ NO RESPONSE →Skip to Q.81

80. Is this because there is no one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

81. Is there any special help that you need to get to or use the bathroom? (SPECIFY)

If respondent indicates any help is received from another person, including cueing or standby assistance, check "Needs Help."

REVIEW RESPONSE ABOVE AND THEN CODE AS APPROPRIATE BELOW.

- 1 ☐ NEEDS HELP FROM ANOTHER PERSON
- 2 ☐ DOES NOT NEED HELP FROM ANOTHER PERSON →Skip to Q.84
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.84
- 9 ☐ NO RESPONSE →Skip to Q.84

82. Are you ever unable to get to or use the bathroom when you need to?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.84
- 7 ☐ UNSURE →Skip to Q.84
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.84
- 9 ☐ NO RESPONSE →Skip to Q.84

83. Is this because there is no one there to help you?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE



84. Think about the support staff who help you with the everyday activities we have been talking about. Do these support staff spend all the time with you that they are supposed to?

- 1 ☐ YES
- 2 ☐ NO
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE
- 95 ☐ NO HOME SUPPORT STAFF

85. Have you ever talked with your case manager or support coordinator about any special equipment, or changes to your home, that might make your life easier?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.88
- 7 ☐ UNSURE →Skip to Q.88
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.88
- 9 ☐ NO RESPONSE →Skip to Q.88

86. What equipment or changes did you talk about? (SPECIFY)

87. Did you get the equipment or make the changes you needed?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ IN PROCESS
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

D. Community Integration/Inclusion

The last few questions I'd like to ask you are about things you like to do in your community.

88. Do you like to go shopping, for things like clothes, books, or music?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.91
- 3 ☐ SOMETIMES
- 7 ☐ UNSURE →Skip to Q.91
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.91
- 9 ☐ NO RESPONSE →Skip to Q.91

89. Do you go shopping?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.91
- 3 ☐ SOMETIMES
- 7 ☐ UNSURE →Skip to Q.91
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.91
- 9 ☐ NO RESPONSE →Skip to Q.91

90. Do you help pick where to go shopping?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE



91. Do you like to go out to eat?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.94
- 3 ☐ SOMETIMES
- 7 ☐ UNSURE →Skip to Q.94
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.94
- 9 ☐ NO RESPONSE →Skip to Q.94

92. Do you go out to eat?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.94
- 3 ☐ SOMETIMES
- 7 ☐ UNSURE →Skip to Q.94
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.94
- 9 ☐ NO RESPONSE →Skip to Q.94

93. Do you get to help pick where you eat out?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

94. Are there people you like to visit with?

- 1 ☐ YES
- 2 ☐ NO →Skip to Q.97
- 3 ☐ SOMETIMES
- 7 ☐ UNSURE →Skip to Q.97
- 8 ☐ UNCLEAR RESPONSE →Skip to Q.97
- 9 ☐ NO RESPONSE →Skip to Q.97

95. Who do you like to visit with? (SPECIFY)

96. Can you see this person/these people when you want?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

97. What other kinds of things do you like to do? (SPECIFY)



98. Do you get to do these things when you want?

- 1 ☐ YES
- 2 ☐ NO
- 3 ☐ SOMETIMES
- 7 ☐ UNSURE
- 8 ☐ UNCLEAR RESPONSE
- 9 ☐ NO RESPONSE

99. Is there anything else you want to talk to me about?

Thank you for talking with me today. I really appreciate all your help. If you need to talk to me again or have other questions, here is how you can reach me. INFORMAL PARTING OF YOUR CHOICE – GOOD-BYE, TAKE CARE, HANDSHAKE, ETC.

E. Interviewer Comments and Observations

Were the core questions used? (circle one) YES NO

What amount of the questions did the program participant answer by him/herself?

- ☐ ALL
- ☐ MOST
- ☐ ABOUT HALF
- ☐ SOME
- ☐ A FEW
- ☐ NONE

Who else provided responses? (If applicable) _____

